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Professional and social support enhances maternal well-being in women with intellectual disability – A Swedish interview study

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A B S T R A C T

Objective: to gain a deeper understanding of the experience of professional and social support during pregnancy and childbirth among women with intellectual disability (ID) in Sweden.
Design/setting: an interview study among 10 women with ID, who had given birth within seven years. Two interviews were performed with each woman and data were analysed with qualitative content analysis.
Findings: the overarching theme was: Professional and social support enhances maternal well-being in women with intellectual disability. The women described that the midwife and other caregivers contributed to their own insights and supported their mother-to-be process. They were mostly satisfied with the professional care and support during pregnancy and childbirth, based on aspects such as continuity, competence and professional experience of the midwives but also professional approach and working methods. Dissatisfaction and confusion occurred when questions were left unanswered or when the women's special needs were not taken into consideration. Family members, friends and colleagues could also have a supporting role and, together with the health staff, contribute to the well-being of the woman.
Conclusions: if professional support and care from midwives and other caregivers is adapted to the special needs of women with ID, it contributes to new insights, enhances well-being and supports the process of becoming a mother. Midwife-led continuity of care together with continuous social support should be offered to pregnant women with ID during pregnancy and childbirth.

Introduction

An intellectual disability is defined as having an intelligence quotient (IQ) below 70, a derogation of adaptive capacity and a debut before 18 years of age (WHO, 1992). In Sweden, the rights of people with intellectual disability (ID) have been regulated since 1994 under the Law on Support and Service for people with Certain Functional Impairment (LSS) (Lag, 1993:387). The principal aims of LSS are to guarantee full participation in society and to allow individuals with ID to choose their own path in life. They have a right to apply for help and support related to their specific needs (10 rights/interventions), for example, daily care, support and other services. This law has in many ways changed the daily lives of young people with ID, who have the possibility to move out of their parent's home into their own apartment or into special homes or group living areas, where they have access to certain services adapted to their specific needs.

Almost all pregnant women in Sweden are registered at antenatal care in the first trimester. The antenatal care is free of charge and almost all care is carried out by midwives, according to a basic programme stated in the national guidelines (Antenatal Care, Sexual and Reproductive Health. Report Number 59, 2008). The basic programme needs to be adapted for women with special medical or psychosocial needs, and one group especially mentioned is women with ID, who should receive special medical and psychological care and support for themselves and their unborn child. However, a recent Swedish study affirmed that there is no uniform model of care for women with ID in pregnancy and childbirth (Hoglund et al., 2013). Moreover, most of the midwives working with antenatal care and in the labour wards had experience of caring for women with ID; nevertheless, they reported uncertainty regarding how to adapt and give advice and requested more knowledge about these women. Further, more than one-third of midwives considered that women with ID should not be

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pregnant and give birth at all (Hoglund et al., 2013). Other studies have reported on negative attitudes among nurses who cared for people with ID compared with nurses who cared for patients with physical disabilities (Lewis and Stenfert-Kroese, 2010), finding that women with chronic illnesses encountered nurses in antenatal education who doubted them to become proper mothers (Blackford et al., 2000).

A recent Swedish study described how women with ID struggled for motherhood and lived with a constant fear of losing custody of their expected or newborn child. The significance of having an ID became evident when the women encountered mixed reactions from partners and relatives, who sometimes suggested an induced abortion. Therefore, the women did not always disclose the diagnosis to the midwife, except if they believed it was beneficial for them (Hoglund and Larsson, 2013).

According to Jean Ball's deck-chair theory on maternal emotional well-being, pregnancy and the postnatal period could be regarded as a time for adaption to a new role. The purpose of all maternity care is to enable a woman to successfully become a mother. In addition, the process involves physiological, psychological and emotional components. The maternal well-being depends partly on the woman's own personality, previous experiences and life-crisis. These factors relate to the care from the midwives and other professional groups at maternity services, attitudes and resources in society and also support from family and peers (Bryar, 2011).

The aim of the study was to gain a deeper understanding of the experience of professional and social support during pregnancy and childbirth among women with ID in Sweden.

Methods

The study had a descriptive design using qualitative interviews. A modified snowball sampling was used and we took several measures to minimise bias related to suggestibility and social desirability. Briefly, the researcher, who is also a midwife, contacted key persons such as school nurses at compulsory schools, psychologists and social welfare officers at rehabilitations centres and staff at the Swedish National Associations for Persons with Intellectual Disability (FUB), where women with ID could be identified. The key persons informed the eligible women about the study. The inclusion criteria were having an ID diagnosis (and therefore known to formal ID services), being able to communicate verbally and having given birth during 2004–2010. Both primiparas and multiparas could participate and all women were encouraged to contact her trustee or another trusted person before agreeing to participate.

Ten women aged 21–41, with ID, who had given birth from 2004 to 2010 were included. The women had a mean number of 2.2 children (range 1–7). Four women were married, three lived with the father of the child, one lived with a new partner and two were single. Five women had custody of their children, but the other five women had not, except for one of them who had custody of some of her children. Seven of these mothers' children lived in foster care and one child lived temporarily with both parents in an institution. We did not ask for, or try to assess, the level of the women's intellectual capacity and we also ignore if their partners had any intellectual disability. However, previous research affirms that pregnancy and childbirth mostly occur among women with mild intellectual disability (National Board of Health and Welfare, 2005.)

If the woman agreed to participate, she was included in the study. The first author visited the women and performed the interviews during two consecutive days in a place chosen by the woman herself. This procedure with repeated interviews, using simple language, gave the women the opportunity to better understand the questions, to reflect about the topic over night and to change, add or withdraw from their previous stories. The interviews were recorded with the women's permission and thereafter transcribed verbatim. We used content analysis to analyse the data (Sandelowski, 2000; Graneheim and Lundman, 2004). The method is described in detail in a previous paper (Hoglund and Larsson, 2013), which reported on the women's experiences of being pregnant and giving birth. This paper reports the findings related to professional and social support during pregnancy and childbirth.

Findings

The analysis resulted in 10 sub-categories, three main categories and one overarching theme, presented in Table 1. An example of the analytical process is shown in Table 2.

The midwife and other caregivers contribute to the woman's own insights

The women generally trusted the midwife and appreciated when they were treated kindly. The women commented on different *characteristics* of the midwife such as her professional experience of caring for women during pregnancy and childbirth as well as her own personal experiences of pregnancy and childbirth. Various *feelings* were expressed towards the caregivers, both warm and positive feelings but also feelings of disappointment and anger. The women commented on the midwife's *working methods* and expressed a need for structured, adapted and repeated information, including brochures that could be easily read and understood. If the midwife was easily available to the woman, it *increased her insights*, her self-confidence and feeling of safety and thus supported the woman to initiate an active mother-to-be process.

The characteristics of the midwife – personality, competence and working experience

The pregnant women spoke about the midwives' characteristics and their care during pregnancy. They mostly felt that a nice, happy, positive and safe midwife treated them. Some women experienced the midwives as good listeners who provided the professional support they wanted and needed. The midwives had a pedagogic and focused awareness in their encounters with the women. If the midwife had been working for a long time and also

Table 1
Theme, categories and sub-categories.

Professional and social support enhances maternal well-being in women with intellectual disability
1. The midwife and other caregivers contribute to the woman's own insights
1.1 The characteristics of the midwife – personality, competence and working experience
1.2 Positive and negative feelings towards the midwife
1.3 Working methods – adapted to the women's needs
1.4 Increasing insights support the mother-to-be process
2. Professional support and treatment
2.1 Appreciation of continuity – of carer as well as of care
2.2 The organisation of care influences the women's well-being
2.3 The women's description of the content of care
2.4 Deficient experience leads to confusion
3. Support from others
3.1 Partner and family could act as co-carers
3.2 Involvement of friends, colleagues and employers

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